

**MEETING OF THE SPECIALISED HEALTHCARE ALLIANCE AT 11.00AM – 2.00PM ON  
WEDNESDAY 14<sup>th</sup> OCTOBER 2015 IN HOUSE OF LORDS COMMITTEE ROOM G**

**Present:**

Baroness Wheeler – Chair

Amanda Croft – MS Trust

Anne Keatley-Clarke – Children's Heart Federation

Brian Gunson – British Liver Trust

Caroline Brocklehurst – Teenage Cancer Trust

Caroline Morrice – GAIN

Charlotte Roberts – MPS Society

Cheryl Gowar – National AIDS Trust

David Ryner – CML Support Group

Fiona Loud – British Kidney Patients Association

Gary Jones – Abbvie

Gordon McFadden – United Amputees Community Charity

Jai Patel – Anthony Nolan

Jerome Penn – Pfizer

Joe Brice – Baxalta

John Kell – MND Association

Joseph Clift – Asthma UK

Kate Eden – Shire (from 12.30)

Luella Trickett - Baxter

Richard Rogerson – Niemann-Pick Disease Group

Sarah Hutchinson – National Voices

Shannah Adams – Marfan Trust

Shona Cleland - Bliss

Stephen Barrie – Novo Nordisk

Stephen Ffoulkes - UKPIPS

Steve Bojakowski – Sobi

Sue Browning – Spinal Injuries Association

Viv Beckett - Genzyme

John Murray – SHCA

Andrew Wilkinson – SHCA

Mark Loughridge – SHCA

## **1 COMPETITION LAW COMPLIANCE**

Members noted their obligations under competition and bribery law.

## **2 APOLOGIES**

Reported: that a number of apologies had been received.

## **3 MINUTES**

Agreed: the minutes of the last meeting on Wednesday 15th July 2015, which would now be published on the Alliance's website.

## **4 MATTERS ARISING**

### **4.1 New members**

Reported: that the Marfan Trust had joined the Alliance, taking the number of patient organisations to 116. Furthermore, following the division of Baxter Healthcare into two companies, Baxalta had joined the Alliance, taking the corporate membership to 17.

### **4.2 Consultation Concerns**

Reported: that members had previously raised concerns about the poor quality of recent consultations

Agreed: that the Alliance would continue to engage with National Voices on this issue.

### **4.3 Conference Report**

Reported: as per the notes on agenda.

## **5 POLICY UPDATE**

### **5.1 NHS England personnel**

Reported: that Dr Jonathan Fielden had been appointed to replace Richard Jeavons as Director of Specialised Commissioning in a permanent capacity, and that in this role Dr Fielden would also serve as deputy national medical director reporting to Sir Bruce Keogh. It had previously been announced that both Richard Jeavons and Dame Barbara Hakin would be leaving their posts at the end of the year.

Noted: that Dr Fielden would be leading the development of a specialised strategy for the future, and that the Alliance would wish to engage with this at the earliest opportunity. Dr Fielden's start date was not yet known.

Considered: That the change of reporting line for specialised services, within the Medical rather than the Commissioning Operations Directorate, was likely to assist the profile of specialised commissioning issues at Board level.

Agreed: that the secretariat would seek to engage with Dr Fielden following his appointment. A meeting with Alliance members as a whole would also be sought.

## **5.2 Department of Health assessment of NHS England performance**

Reported: as per the notes on agenda.

Considered: that the Department of Health's references to multi-year budgets had been vague, but that any further developments would need to be monitored closely for their potential impact on specialised commissioning.

## **5.3 NHS finances**

Reported: that NHS England's most recent Board papers forecast a 2015/16 specialised commissioning overspend of £72 million, £70m of which related to overspending in the Cancer Drugs Fund.

Considered: that while the specialised commissioning budget was now broadly balanced, in contrast to previous years, cost drivers within specialised services were likely to see a significant gap between costs and resources re-open in future unless preventive action was taken.

## **5.4 Prescribed Specialised Services Advisory Group (PSSAG)**

Reported: as per the notes on agenda.

Considered: that PSSAG's processes were operating below the standards of transparency and engagement which Alliance members expected and that, in the event of future service devolution proposals being presented to the committee, this could have a significant impact. Robust engagement was of particular importance for PSSAG given its independence from NHS England.

Agreed: that Alliance members would need to consider how to prioritise this issue in future.

## **5.5 Parliamentary developments**

Reported: as per the notes on agenda

# **6. NHS ENGLAND'S SPECIALISED COMMISSIONING POLICY PROCESS**

## **6.1 Policy development process changes**

Reported: that, having been criticised for its opaque and convoluted policy development process in the recent prioritisation consultation, NHS England had been developing improvements to its processes which were due to be announced imminently. These were shared with the Alliance's secretariat in advance. The new process was expected to take approximately six months, with a focus on demonstrating the quality of proposals before NHS England accepted them within its work programme. For the majority of decisions to be taken for the

2016/17 financial year, NHS England had appointed an external provider to lend process support.

Noted: that NHS England was expected to publish the confirmed list of policies to be developed for 2016/17 shortly. The expectation was that decisions would be taken and published shortly after the beginning of the financial year.

Considered: that changes to the policy development process were long overdue, particularly when the large policy backlog was taken into account. These changes were therefore welcomed by members and were seen as endorsement of the Alliance's policy process proposal, which had been shared with NHS England earlier in the summer.

Agreed: that the secretariat would distribute further information on NHS England's new approach following the meeting, once cleared to do so by NHS England.

## **6.2 Process assurance and transparency**

Reported: that although all parties were agreed in principle that the minutes of the Patient and Public Voice Assurance Group (PPVAG) should be published, NHS England had delayed publication repeatedly. The Chief Executive's office had asked to review the minutes and was in the process of proposing amendments. Given the group's focus on process assurance and transparency, PPVAG members wished to see the minutes of their meetings published as soon as possible. Given the circumstances, the Director had suggested that the Alliance could publish PPVAG's minutes discreetly on its website pending publication by NHS England.

Considered: that it was not the preference of the Alliance to publish unilaterally, but that transparency was an important point of principle to be upheld. NHS England had been given many opportunities to publish the minutes but had as yet failed to do so. Alliance members saw it as important to have the opportunity to see the minutes given the role of the PPVAG as a body representing patients' interests and assuring NHS England's work.

Noted: that the minutes should be removed from the Alliance's website as and when NHS England published them.

Agreed; that the secretariat should have clearance to publish the minutes of the PPVAG on the Alliance's website at the beginning of November in the unfortunate event that NHS England had still failed to do so..

## **6.3 NHS England's generic commissioning policies**

Reported: as per the notes on agenda.

Considered: that, if delivered, NHS England's pledge to consult on the interim funding process for patients in urgent critical need represented welcome progress following intensive campaigning by the Alliance and its members.

Noted: that there remained significant dissatisfaction with the IFR process.

## **7. DEVOLUTION OF SPECIALISED COMMISSIONING**

Reported: that the Cities and Local Government Devolution Bill had passed to the Commons from the Lords on 21<sup>st</sup> July and was due its second reading on 14<sup>th</sup> October. Members were reminded of the significance of the bill for specialised commissioning. The secretariat had provided a briefing for relevant parliamentarians and, alongside the Chair, had met the new Shadow Health Secretary Heidi Alexander along with House of Lords Shadow Health Spokesman Lord Hunt on 12<sup>th</sup> October. Jon Rouse, Director General for Social Care, Local Government and Care Partnership at the Department of Health, had also been contacted, following up on a meeting held in the summer.

Considered: that there were significant risks, alongside some opportunities, from future devolution in respect of specialised care, but that the bill presented more immediate concern. Members particularly wished to see national specifications preserved in any devolution settlement. It would be important for the Alliance to communicate with Ministers at the Department for Communities and Local Government, who were taking the bill through parliament.

Agreed: that the secretariat should contact DCLG Ministers, continue its parliamentary engagement and provide further updates to members on the bill's progress.

### **7.1 DevoManc**

Reported: that detail on how specialised services might be planned and managed within Greater Manchester in future were worryingly absent.

Considered: that while many specialised services could be managed effectively at regional level, this was not the case in every area and a varied model risked confusion and a dilution of accountability. The provision of specialised services in areas not subject to devolution would be of equal concern. There was support for closer engagement with the Greater Manchester authorities on these issues.

Noted: that recent comments from the Chief Executive of Wigan Council about diverting resource from specialised to preventative services demonstrated the potential risks devolution posed to specialised care.

Agreed: that the Alliance would write to Ian Williamson, Interim Chief Officer for Health and Social Care Devolution in Greater Manchester. Further updates would also be provided to members on DevoManc developments.

## **8 SPECIALISED TARIFF DEVELOPMENTS**

Reported: that Monitor and NHS England were continuing to develop proposals for specialised tariff payments for 2016/17 which were likely to see the inclusion of a marginal rate for specialised services. This would act as a crude instrument to bear down on specialised activity levels. The Alliance's lunch guest, Anita Charlesworth, was chairing a committee considering these proposals. An engagement document had been expected in October but Monitor's most recent Board papers indicated that this had been dropped.

Considered: that the emphasis in NHS England's commissioning intentions

document on assessing and reimbursing the 'actual cost' faced by providers was important. There was concern about the levels at which activity baselines would be set in respect of the marginal rate and how flexibly this would be able to adapt to patient need. These changes were thought to be part of a broader strategy from NHS England in order to drive savings from providers, suppliers and others. The question of whether or not high cost drugs and devices would fall within any marginal rate mechanism was thought to be crucial. The Alliance would need to monitor and engage with these developments but had decided not to join Anita Charlesworth's committee but rather attend a meeting by invitation .

Noted: that providers' ability to object to new tariff proposals was likely to be weakened significantly as a result of a recent Department of Health consultation.

Agreed: that the Alliance should maintain its established policy and advocacy position in relation to potential tariff changes, engaging selectively where appropriate and monitoring developments insofar as they could affect patient access to care.

## **9 NATIONAL AUDIT OFFICE REVIEW**

Reported: as per the notes on agenda.

Considered: that the NAO study provided an excellent opportunity for members to demonstrate the progress or challenges faced by their services since April 2013. In particular, given the ongoing broader context of changes to commissioning structures, the report might play an important role in highlighting the benefits of national commissioning, as well as touching upon difficulties in practice.

Noted: that the final NAO report would be passed on to the Public Accounts Committee. It would be important for the Alliance to demonstrate the strength and breadth of its membership in delivering good case studies to the NAO.

Agreed: that members would share case studies with the secretariat as soon as possible and the Alliance would continue to engage with the NAO throughout the preparation of its report on specialised commissioning.

## **10 LUNCH GUEST**

Reported: as per the notes on agenda.

## **11 2016 WORK PLAN**

The secretariat delivered a presentation reviewing the Alliance's activities and impact in 2015 and outlining flagship proposals for members to consider for 2016.

Considered: that the balance struck between being robust and being constructive through the Alliance's engagement had been well calibrated, despite challenging circumstances. Initial soundings had been taken from Lord Warner on his interest in chairing a potential Commission on specialised services. It was possible that NHS England would take forward a strategic review of the kind intended for the Commission, but this would be an equally welcome outcome.

Noted: the importance of seeking NHS England's buy-in to be assured, as far as possible, that the recommendations of a Commission were taken up. Capacity concerns would need to be managed by the secretariat.

Agreed: that members endorsed the proposed approach for 2016, including the proposal to establish a Commission building on the Carter Review. The secretariat would circulate the slides to members as a whole for any further comments and final approval by written procedure.

### **11.1 Appointment of secretariat**

The incumbent secretariat left the room and, in their absence, members agreed to retain JMC Partners for 2016.

## **12 REPORT ITEMS**

Reported: as per notes on agenda.

- 12.1 Meeting with Noel Gordon**
- 12.2 UK Rare Disease Forum report**
- 12.3 AAR response and roundtable**
- 12.4 Meeting with Shelford Group**
- 12.5 NHS Innovation Expo**
- 12.6 Welsh orphan and ultra-orphan drug appraisal process**
- 12.7 Review of Clinical Reference Groups**
- 12.8 Vanguard**
- 12.9 Myeloma UK newsletter**
- 12.10 Patient and Public Voice Assurance Group**
- 12.11 Meetings during July to October**

Considered: that NHS England's commissioning intentions indicated that a fully devolved budget was in prospect for cancer services. In the short term this was thought to be exceptional but, if successful, there was a likelihood that NHS England would seek to replicate the model elsewhere.

Noted: the importance of members contributing to the Alliance's work as part of the UK Rare Disease Forum.

## **13 DATES OF NEXT MEETINGS**

Agreed: that the secretariat would confirm the Chair's availability for quarterly meetings in 2016 and provide dates to members as soon as possible.

## **14 ANY OTHER BUSINESS**